

Autoimmune diseases misdiagnosed as psychosomatic can lead to long-term damage to physical and mental well-being

March 2 2025



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A "chasm of misunderstanding and miscommunication" is often experienced between clinicians and patients, leading to autoimmune diseases such as lupus and vasculitis being wrongly diagnosed as psychiatric or psychosomatic conditions, with a profound and lasting

impact on patients, researchers have found.

A study involving over 3,000 participants—both patients and clinicians—found that these misdiagnoses (sometimes termed "in your head" by patients) were often associated with long-term impacts on patients' physical health and well-being and damaged trust in health care services.

The researchers are calling for greater awareness among clinicians of the symptoms of such diseases, which they recognize can be difficult to diagnose, and for more support for patients.

Autoimmune rheumatic diseases such as [rheumatoid arthritis](#), lupus and vasculitis are chronic inflammatory disorders that affect the immune system and can damage organs and tissues throughout the body. They can be very difficult to diagnose as people report a wide range of different symptoms, many of which can be invisible, such as extreme fatigue and depression.

Dr. Melanie Sloan from the University of Cambridge led a study exploring patient-reported experiences from two large groups, each of over 1,500 patients, and in-depth interviews with 67 patients and 50 clinicians. The results are published in *Rheumatology*.

Patients who reported that their autoimmune disease was misdiagnosed as psychosomatic or a [mental health condition](#) were more likely to experience higher levels of depression and anxiety, and lower mental well-being.

For example, one patient with multiple [autoimmune diseases](#) said, "One doctor told me I was making myself feel pain and I still can't forget those words. Telling me I'm doing it to myself has made me very anxious and depressed."

More than 80% said it had damaged their self-worth and 72% of patients reported that the misdiagnosis still upset them, often even decades later. Misdiagnosed patients also reported lower levels of satisfaction with every aspect of medical care and were more likely to distrust doctors, downplay their symptoms, and avoid health care services.

As one patient reported, it "has damaged my trust and courage in telling doctors very much. I even stopped taking my immunosuppressive medicine because of those words."

Following these types of misdiagnoses, patients often then blame themselves for their condition. As one individual described: "I don't deserve help because this is a disease I've brought on myself. You go back to those initial diagnoses, you've always got their voices in your head, saying you're doing this to yourself. You just can't ever shake that. I've tried so hard."

One patient described the traumatizing response their doctor's judgment had on them: "When a rheumatologist dismissed me, I was already suicidal. This just threw me over the edge. Thankfully, I am terrible at killing myself. It's so much more challenging than you think. But the dreadful dismissiveness of doctors when you have a bizarre collection of symptoms is traumatizing and you start to believe them, that it's all in your head."

Dr. Melanie Sloan, from the Department of Public Health and Primary Care at the University of Cambridge, said, "Although many doctors were intending to be reassuring in suggesting a psychosomatic or psychiatric cause for initially unexplainable symptoms, these types of misdiagnoses can create a multitude of negative feelings and impacts on lives, self-worth and care.

"These appear to rarely be resolved even after the correct diagnoses. We

must do better at helping these patients heal, and in educating clinicians to consider autoimmunity at an earlier stage."

Clinicians highlighted how hard it was to diagnose autoimmune rheumatic diseases and that there was a high risk of misdiagnosis. Some doctors said they hadn't really thought about the long-term problems for patients, but others talked about the problems in regaining trust.

As one GP from England highlighted, "They lose trust in anything that anyone says...you are trying to convince them that something is OK, and they will say yes, but a doctor before said that and was wrong."

However, there was evidence that this trust can be rebuilt. One patient described having been "badly gaslit by a clinician," but that when they told the clinician this, "She was shocked and had no idea ... She was great. Took it on the chin. Listened and heard. Apologized profusely ...For me, the scar of the original encounter was transformed into something much more positive."

Mike Bosley, autoimmune patient and co-author on the study, said, "We need more clinicians to understand how a misdiagnosis of this sort can result in long-standing mental and emotional harm and in a disastrous loss of trust in doctors. Everyone needs to appreciate that autoimmune conditions can present in these unusual ways, that listening carefully to patients is key to avoiding the long-lasting harm that a mental health or psychosomatic misdiagnosis can cause."

The study authors recommend several measures for improving support for patients with autoimmune rheumatological diseases. These are likely to apply to many other groups of patients with chronic diseases that are often misunderstood and initially misdiagnosed.

They propose that clinicians should talk about previous misdiagnoses

with patients, discuss and empathize with their patients as to the effects on them, and offer targeted support to reduce the long-term negative impacts.

Health services should ensure greater access to psychologists and talking therapies for patients reporting previous misdiagnoses, which may reduce the long-term impact on well-being, health care behaviors, and patient-doctor relationships. Education may reduce misdiagnoses by encouraging clinicians to consider systemic autoimmunity when they assess patients with multiple, seemingly unconnected, physical and mental health symptoms.

Professor Felix Naughton, from the Lifespan Health Research Center at the University of East Anglia, said, "Diagnosing autoimmune rheumatic diseases can be challenging, but with better awareness among [clinicians](#) of how they present, we can hopefully reduce the risk of misdiagnoses.

"And while there will, unfortunately inevitably, still be patients whose condition is not correctly diagnosed, with the correct support in place, we may be able to lessen the impact on them."

More information: Melanie Sloan et al, "I still can't forget those words": mixed methods study of the persisting impacts on patients reporting psychosomatic and psychiatric misdiagnoses, *Rheumatology* (2025). [DOI: 10.1093/rheumatology/keaf115](https://doi.org/10.1093/rheumatology/keaf115)

Provided by University of Cambridge

Citation: Autoimmune diseases misdiagnosed as psychosomatic can lead to long-term damage to physical and mental well-being (2025, March 2) retrieved 10 March 2025 from <https://medicalxpress.com/news/2025-02-autoimmune-diseases-misdiagnosed-psychosomatic->

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